MINUTES

NATIONAL WORKSHOP ON

SERVICES UNIQUE TO BLIND PERSONS WITH DIABETES

BOSTON, MASS.

OCT. 31 . NOV. 2,1977

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AMERICAN FOUNDATION FOR THE BLIND, INC.
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ON

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SPONSORED BY THE

AMERICAN FOUNDATION FOR THE BLIND

LENOX HOTEL

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Mr. Asenjo, Workshop Coordinator, greeted the participants and set the goals for the workshop. Judy Griffin, R.N., Nurse Educator, Diabetes Education Center, Minneapolis, Minnesota, opened the meeting remarking that many different disciplines were represented in this workshop and it would be necessary to reach or find a comprehensive approach to the management of the blind diabetic. Diabetic management has been accepted for a long time but the team approach is the most efficient way of working with the diabetic and particularly with the visually handicapped diabetic. The center of the team is always the diabetic who is being served.

A major element to focus on is the purpose of this workshop. Why are we concerned about services to the blind diabetic? Diabetes has been recognized since 2,000 B.C. but for many years diabetes was not a major concern as there was no treatment method. Prior to 1921 juvenile diabetics only lived one to two years after diagnosis. With prolonged life expectancy after the development of insulin, greater problems were recognized. Some people felt that insulin was going to be a panacea but they were rudely awakened when prolonged life expectancy exposed complications of eye, kidney and cardiovascular diseases. These problems began to emerge in the early 1940's.

In the report to the National Commission on Diabetes to the United States Congress in 1975 it was stated that it was estimated that people with diabetes are 25% more prone to blindness than those people without diabetes. They also reported that 63% of persons with juvenile diabetes show signs of eye changes within 15 years after diagnosis. This is a very significant figure. Presently, 40 to 70% of clients in rehabilitation centers for the blind in the United States have a second major disability in addition to blindness. Many of the clients have diabetes as this second major disability. One center recently reported 60% of their client case load were diabetic. Diabetes is the second leading cause of "new blindness" in the United States and the leading cause of blindness among adults in the United States.

Naturally, diabetes is a major concern of all of us working in the blindness field in the United States. The American Foundation for the Blind invited us here to pool our resources, knowledge and creativity and hopefully to come up with recommendations that will create services to better serve the visually handicapped diabetic.

Medical Services

Discussants: Lloyd Aiello, M.D. and
Donald M. Barnett, M.D.
Joslin Clinic
Boston, Massachusetts

Dr. Aiello said that he would begin by presenting concepts of diabetic eye conditions and Dr. Barnett would mold the eye into the total patient. From Dr. Aiello's point of view, he hoped that the workshop would bring some understanding of the ocular problems of the diabetic and how that ocular disability fits into the systemic problem and diabetes. He stated that up to the present time this type of coordination has not been molded into the total program for the diabetic. It had already been mentioned that patients with 63% of juvenile diabetes will develop retinopathy. About 18% of them after 20 years will develop the proliferating type which leads to blindness and about three percent of these juvenile diabetics become totally blind. This is to say nothing about the adult diabetic. The adult-onset diabetic has a much lower incidence of blindness, somewhere about five percent or less. Also glaucoma occurs in four to six percent of diabetics as opposed to two percent of the general population. Dr. Aiello pointed out that cataracts occur more often in people under the age of 40 with diabetes than with the non-diabetic. In about 400,000 patients who have cataracts, under the age of 40, most of these are diabetic.

One of the major concerns of Dr. Aiello was the fact that once a diabetic patient becomes "legally blind", he is eligible for all kinds of services. However, the patient who is having eye problems resulting from diabetes and has not reached the point of "legal blindness" receives no services. There is some trend for this concept to change and it is hoped before too long. Dr. Aiello feels that there is no magic number which should make services possible; in fact the term "legal blindness" should be discarded. He then gave a thorough description of the anatomy of the eye and how diabetes may affect its functioning.

Dr. Aiello emphasized the fact that macular degeneration (loss of central vision) is a major cause of "legal blindness" because

of diabetes. Another disease is "new vessel" disease in which massive hemorrhage occurs and in which cataracts develop, where scar tissue develops and then pulls the retina off resulting in total blindness. Dr. Aiello summarized his discussion by emphasizing the importance of the patient in controlling his diabetes. There is a study in the planning stage in the Institute of Metabolism and Arthritis which will compare diabetics on very strict control to those on a routine control. This study will involve about 16-20 clinical centers in the United States.

Dr. Aiello emphasized the absolute necessity to begin serving the diabetic patient when an eye problem is first recognized. Services should not have to wait until the patient reaches the magic number of 20/200. The patient who is waiting vitrectomy should also be eligible for services, and not depend on whether vitrectomy diagnosis is positive for restoration or not. The kind of service that the person receives must be highly individualized. Braille or other communication skills may come at a time when mobility training is not indicated and vice versa. When economic stress is brought about because of an eye problem, counselling and other services should be made available.

Dr. Barnett's remarks:

Dr. Barnett felt he had to do more than lecture on his favorite subject which is diabetes so he had prepared a "handout" on which he would base his discussion. (See Appendix I.)

Dr. Barnett felt that because the juvenile diabetic has the most evidence of retinopathy, the workshop should emphasize that group. He also stressed the importance of individualizing patients. The term used by Dr. Barnett and others is juvenile onset of diabetes in youth (JODY) and adult onset of diabetes (AODM). From the material handed out, he discussed the acute diabetic syndrome and the chronic diabetic syndrome in relation to JODY. It is important to understand the word syndrome as this term is increasingly becoming a part of the medical student's world. Most patients, and certainly most laymen have been raised to believe that a disease goes from A to B to C which is a very simplistic approach. However, the medical student is rapidly being cavorted into a concept that most problems that now are settling out which we worried about, i.e., hypertension, gout, and diabetes are really inherited metabolic disorders with diabetes being the most common. It is made up of two parts; i.e, acute diabetes and chronic diabetes. The argument is whether Acute (A) leads to Chronic (C).

It is known that the acute diabetic totally lacks insulin and even if there is a remission, it is short lived; within five years the acute diabetic is totally dependent on insulin. If one develops diabetes below the age of 20, 95% of those patients will become totally dependent on insulin.

The chronic syndrome is made up of a vasculopathy concept and neuropathy which has nothing to do with blood vessels. These are the two major components of the chronic diabetes syndrome. The small blood vessels have one layer whereas the large blood vessels have three layers. Dr. Barnett pointed out that one layer vessels exist in the eye and the kidney, and the large vessels relate more to coronary artery disease. The small blood vessel disease is more frequent with the juvenile diabetic and 1/4 to 1/3 of the juvenile diabetic patients become involved with serious retinopathy; whereas in the adult population less than ten percent have serious retinopathy problems. The large vessel disease is more of a problem with the adult diabetic which shows up more in the legs. In juvenile cases when complaints are reported with respect to leg problems it is usually neuropathy and rarely a large vessel problem. Neuropathy in the adult occurs also but takes on slightly different forms but relates mainly to sensation and motor-neuropathy.

The coronary artery disease comes along as a function of duration of diabetes added to age. It has already been said that five years of diabetes in children involves total diabetes. Between the 10th and 20th year after diagnosis one should be aware of the possibility of onset of retinopathy. Between the 20th and 40th years be aware of coronary artery disease.

Dr.Barnett then went on to give a thorough explanation of the causes of neuropathy making a clear distinction between neuropathy and vasculopathy. As a rule the neuropathy exists as a problem due to the length of the nerve from the spinal cord so generally the neuropathy occurs in the stocking area. If the diabetic with a visual problem does not complain about feet or leg problems but indicates having hand problems then one does not think of neuropathy but, rather there should be an examination of the neck area.

Psycho-Social Services

Discussants:

Judith Giarratana, R.N.
Retina Association
Boston, Massachusetts

John Muldoon, M.P.H., Ph.D.
Ravenswood General Hospital-Medical Center
Chicago, Illinois

At the Retina Associates approximately 15,000 patients are seen per year. Their policy is to see any patient with a need. Many of these patients have very practical fears such as wanting to know how long will it be before they are blind and is it painful? If blindness is total, will it be a sudden or slow blindness? The patients who have the greatest complaints are those between 20/70 and 20/200 visual acuity. They feel that they have no place to go for service and are in limbo.

Directly connected with these fears are those related to employment, the continuing maintenance of their family and careers. Other fears include those of diabetic women whether or not they should become pregnant and those of men in relation to impotency. The diabetic woman who has fears of pregnancy is recognizing the fact simply because diabetes after 10 or 15 years duration with the additive complaints of vascular and retinopathy problems makes chances for normal pregnancy hazardous both for the fetus and the pregnant woman.

In some instances as Ms. Giarratana indicated, some of the patients she works with welcome the onset of total blindness in order to settle the frustration which occurs between 20/30 and the onset of total blindness. It is important to help the diabetic to understand that their fear of becoming totally blind is unfounded as total blindness results in approximately three percent of diabetics.

Ms. Giarratana outlined four areas of crisis: (1) the newly diagnosed diabetic with retinopathy, (2) the diabetic with fluctuating vision between 20/30 and 20/200, (3) the "legally blind" diabetic who realizes that there may not be any hope, (4) the diabetic who has been referred to an agency for the blind which may be temporary until a vitrectomy or other surgery may be performed. Ms. Giarratana stressed the importance of providing the patient in all stages with adequate counselling in which the ophthalmologist must play a major role.

Along with fears, the patient very often has guilt feelings with respect to retinopathy, very often related to the failure of maintaining adequate control. It was pointed out that very often the diabetic patient is more willing to discuss fears with the nurse, social worker and counsellor rather than with the ophthalmologist.

The patient very often resents the chronic disease of diabetes rather than some of the other complications such as blindness. The fear of an early death also creates anxiety in the patient. As already indicated, diabetes may bring on early death: however, this is no reason for an agency providing services to blind people to refuse or reduce services to a blind diabetic. The

blind diabetic should be given equal opportunity to pursue a chosen occupational goal.

The conflict of dependence-independence was discussed and the need for counselling in these areas was pointed out. The loss of independence very often creates anger and frustration which too often is taken out on the parent or spouse. Suicidal tendencies that some diabetics have are the result of feelings of uselessness, worthlessness, helplessness and hopelessness.

John Muldoon's remarks:

Mr. Muldoon has been involved in the development of systems of care and his comments reflected his past experiences as a clinician and planner. He grouped his comments around three topics: (1) Diabetes, as illness, (2) Diabetes as a phenomenological experience, (3) socio-ecological characteristics of appearances. Illness is of two types - acute and chronic. The characteristic of the acute illness is that it moves in stages, A-B-C-D. In acute illness you have diagnosis, treatment, and you do not usually need rehabilitation. In chronic illness you have the same steps, symptoms going to diagnosis, treatment, and you do need rehabilitation.

In some ways there is no such thing as diabetes; it is an abstraction and has to do with some symptoms people share, a bio-chemical phenomena. Diabetes is a unique non-reparable experience and must be treated in that way. Treatment must therefore be personalized taking into consideration who is the person and what are his needs which takes us to diabetes as a phenomenological experience. This is an intensive personal experience which is determined by bio-chemical phenomena. It is also determined by the psychological and developmental characteristics of the person. Looking at diabetes as a phenomenological experience, one must remember that diabetes is a primary insult to the self-concept - it radically affects the person's sense of well-being. It establishes in a very dramatic way the person's sense of vulnerability. Diabetes is an on-going psychological experience and there is an intense personal involvement in its management. It makes a person dependent on his own personal judgement which is a heavy psychological burden. There is preoccupation with diet, insulin, exercise and proper management because of possible unhappy experiences in future life.

Diabetes is an intense experience because it introduces the person to a tremendous array of helpers; he moves from specialist to specialist. The diabetic is not a "fun" person with whom to work and consequently we are very happy to move the person on to other specialists. Diabetes attacks the Health System which is most vulnerable as it works best with healthy people. It is the sick person with whom the system has trouble; any chronic illness attacks the Health System. The value of the

person is lost in this bio-chemical warfare and very often the diabetic does not feel like a person and hides behind the fact that he is a diabetic.

If one has a certain illness that responds to a mechanistic diagnosis, it is possible to respond very well. Sometimes we talk about holistic medicine, comprehensive rehabilitation as if these might be the answers, but unfortunately we still have the same nouns with the adjectives, holistic medicine, comprehensive rehabilitation, etc., but we are not yet to the point where we have holistic and comprehensive care. Unfortunately, we designed institutions as sheltered workshops and the most infamous workshops are hospitals and universities. Some students go to universities and prosper and some do not; some people go to the hospital and prosper and some do not. We must design buildings and structures in terms of what we are trying to do in them. The crisis in the Health System is caused by chronic illness not by acute illness.

Instructional Services

Discussants:

Sandra Kolterman
Counsellor/Teacher
State Department of Rehabilitation
Oakland, California

Tom Hanson
Assistant Professor
Rehabilitation Teaching Program
Cleveland State University

Ms. Kolterman said that an outcry in her state for more information related to diabetes and blindness brought about the compiling of data regarding insulin, syringes, urine testing methods, etc. Additionally, in-service training programs were conducted for rehabilitation counsellors, public health nurses and other professionals working in the field of rehabilitation. Although the request for these training programs came from the field, very often the same source was critical of the in-service training. Too often information is so medically oriented that it should be presented by medical professionals. However, medical professionals apparently have too little time to conduct these in-service training programs.

Ms. Kolterman strongly recommended that rehabilitation workers should keep a kit of the various devices for self-management by the diabetic person and the devices should be described to the diabetic as well as to the medical personnel. The diabetic

and medical personnel should also be aware of the places where these devices can be purchased. She distributed materials related to diabetes and blindness: (1) Aid/Appliance and Description; (2) Warning Signs of Insulin Reaction; (3) a bibliography on Diabetic Cooking. (See Appendix II.)

Ms. Kolterman emphasized the importance of glucose urine testing. However, she just as strongly emphasized the point that no system presently available to blind people is adequate. The audible testing instrument is not on the market and the "yeast testing" method is cumbersome. In Ms. Kolterman's description of the various insulin syringes she commented as to which were easy to use by a blind person and those which were almost hazardous for use by a blind diabetic. Ms. Kolterman suggested that "Instant Glucose" made available through the Diabetes Association of Cleveland should be made more available through adequate distribution through many resources in addition to pharmacies as it is not a prescriptive item.

Tom Hanson's remarks:

Mr. Hanson's talk dealt more with the dependent-independent variables, particularly true if self-management by the diabetic is expected. The blind diabetic is concerned with the preparation of food within diet limitations, the injecting of insulin and with employment. Each of these is of major importance to survival. He also said that the role of the family is a major factor. How does the family feel about the blind diabetic within its constellation? What are the conflicts within the family structure because of the blind diabetic? How does the blind diabetic feel about his family? He feels that if there are major guilt feelings within the family, consultative services can be secured from local diabetes associations or from a rehabilitation counsellor if knowledgeable about diabetes.

Mr. Hanson felt that Ms. Kolterman's information sheet was of importance particularly to individuals involved in instructional areas. He stressed the importance of instructors in orientation and mobility, communications, industrial arts and others involved in the rehabilitation process to be aware of the timing for instructions for diabetic blind people. For example, should orientation and mobility be given early in the morning, before noon or in the afternoon? Should communication skills be followed by another instructional course which requires acute tactual perception.

An individual who enters a program where new activities are introduced requires extra care in order to make necessary changes

in caloric and insulin intake. Instructional services can vary with the visual stabilization of the individual. If a blind person with diabetes is receiving services which are directly related to blindness (orientation and mobility and braille) and because of remission regains some useful vision, the instructional program may have to be altered.

Mr. Hanson further emphasized the need for agencies serving the blind diabetic to give consideration to energy conservation in the area of personal management services; care should be taken to arrange homes, particularly the kitchen area so that food preparation and other household chores can be done with minimal energy waste.

Also problems other than visual or renal must be considered with the diabetic. One major area is that of amputation if the blind diabetic has a leg or legs amputated and is confined to a wheelchair. How then does this person function in the home or at work? Are counters on stove tops at a comfortable level for the blind diabetic in a wheelchair; are washing machines and dryers designed for the person in the wheelchair? Finally, Mr. Hanson expressed the importance of having someone fully knowledgeable in the area of diabetes and blindness available on a national level as a consultant to agencies serving the blind diabetics.

Vocational Services

Discussants: Larry Duncan
Area Supervisor
Massachusetts Commission for the Blind
Boston, Massachusetts

Mr. Duncan supported the other discussants with respect to the need to develop a system whereby diabetics experiencing early eye problems should receive services from the agency which can best serve the patient. If the eye condition has reached the acuity which makes work-related tasks difficult, that person should be eligible for services through the agency designated to serve blind and/or visually handicapped persons.

Mr. Duncan recognized all the problems involved with respect to job selection for the blind diabetic. Because of possible infection, the blind diabetic should not be placed in a job where high risk injury is present. The need of a vocational counsellor to understand the problem or lack of problems on the part of the blind diabetic is most important. Regardless of life expectancy the blind diabetic should receive the same opportunities in the vocational rehabilitation program as does

the non-diabetic blind person. The opportunity for work evaluation and adjustment services should be equally available to blind diabetics through rehabilitation center programs, as well as professional training on the college or university level.

It is recognized that there are some diabetic blind persons whose physical status will not permit them to engage in the day-to-day labor force, although very often these individuals are anxious to be provided employment. Counselling of the most expert degree must be made available to these people in order to face realistic conditions. The blind diabetic who has kidney failure and who must make use of dialysis should be provided this service through any resource including agencies serving blind persons as there are many persons on dialysis (not blind) who are employed and carry out their responsibilities in the labor force. Mr. Duncan constantly emphasized the necessity to provide service to the diabetic blind person on the same level as the non-diabetic blind person.

Lorrayne Phillip's remarks:

Ms. Phillips indicated that she was very new to the Office for the Blind and Visually Handicapped, Department of Health, Education, and Welfare, Washington, D.C. and that ther attendance at the workshop was one of learning rather than contributing. From the deliberations, she was made aware of the needs of the blind diabetic and she hoped that the recommendations resulting from the workshop could be synthesized into proposals and submitted to the Central Office for funding consideration.

Leisure Services

Discussants:

Joyce Schulz, R.N.
Rehabilitation Services
Minneapolis Society for the Blind

Arlene Gordon, M.S.W.
Associate Director
Program Services
The New York Association for the Blind

Prior to coming to the workshop in Boston, Ms. Schulz met with some blind diabetic clients in her agency and obtained from them various thoughts with respect to leisure time activities. From the information she was able to gather, leisure time activities for blind persons with diabetes is no different from blind persons without diabetes. It is a highly individualized matter and each person seeks the kind of leisure time activity desired. The emphasis placed on one activity changes periodically; for example, ceramics may be the vogue and in a matter of months it may change to macramé.

The only difference which may influence the leisure time activity of the blind diabetic is accompanying complications, poor stamina and neuropathy. These are greater deterents than those related to the visual problem. It has already been indicated that you cannot divorce blindness from diabetes but diabetes is the primary problem.

Prior to the availability of syringes which could be used by the blind diabetic, and due to the inconvenience involved in constantly asking someone to prepare the syringe for insulin intake, the blind person attempted to control his diabetes by diet only, which was a dangerous approach. Exercise is an important part of anyone's life including the blind diabetic. However, when exercise is involved the diabetic has to be aware of the changes required either by diet or insulin. Ms. Schulz said that leisure time activities can be anything, it is what anyone wants it to be dancing, hockey, knitting, etc. True that some of these activities require some adaptation for the blind diabetic but knowing that a person who is blind and diabetic can continue to participate enables the diabetic blind individual to overcome feelings of uselessness, worthlessness, hopelessness, etc.

There was a lengthy discussion with respect to decreasing insulin because of additional activities or a food exchange for additional activities. It was mentioned that within five years more scientific data will be available on insulin and possible food exchange in relation to exercise. It was questioned as to whether all blind diabetics entering a rehabilitation center should go through a diet education experience. It was felt that kind of training should be given to the blind diabetic only after the client had been in the rehabilitation center for one month as blindness alone is sufficiently overwhelming. However, when the clients are ready, they do go through an educational program on diabetes in certain states. There was an expression that the attending physician in a community should provide the diabetic with educational information related to diabetes. However, most physicians in most communities are not knowledgeable enough to provide properly the needed information although this is not true in some of the more highly sophisticated communities. Dietitians also must upgrade their knowledge with respect to caloric intake, and persons who are involved and responsible for serving diabetics should upgrade their knowledge every two to three years in a diabetic training program in order to take advantage of new information.

Arlene Gordon's remarks:

Ms. Gordon began her talk by pointing out the various ages where leisure time is used: for example, there is the young child who

is just growing up, the pre-school child, there is the child who is just entering school, then the person in junior high school and then the adult. In each growth area the leisure time is different but can be relaxing, satisfying and helpful in developing feelings of personal self-worth and self-esteem.

Ms. Gordon wanted to go beyond and discuss leisure activities and try to pull together many of the questions which had been raised during the last two days. These were questions which would need discussion and resolution, particularly on how the problem of the blind diabetic can be resolved on a national level. She also indicated that perhaps a legislative mandate could partially resolve the problem of the blind diabetic. Ms. Gordon indicated that it was difficult for her to separate leisure time activities: for example, when one goes to work a coffee break and/or the lunch hour may be leisure, after working hours some of the employees may get together for entertainment and this is leisure.

How do we become involved in early intervention? How do we provide early education to the blind diabetic and how do we provide an understanding of blindness and diabetes to the family? It is not sufficient to educate just the blind diabetic because that person lives with the family, lives in a neighborhood, lives in a community, so all of these elements must be involved in an educational program.

Ms. Gordon was concerned about some of the questions which had been raised, such as when does an agency serving blind people become involved in providing services to the blind diabetic or to his family? It is her feeling (whether the patient or the family even mention blindness or any other problem related to diabetes) that good counselling can help the person understand the need for other services. Blindness is not the end of the road and through adequate services the blind diabetic can continue to function. Another point that Ms. Gordon brought out was that of the whole employment area as part of the psycho-social aspects of the blind diabetic. Sometimes employment is not discussed simply because the counsellor or the person responsible for placement does not believe that the blind diabetic can truly function in an employment setting.

Ms. Gordon indicated that all of the various threads that had been discussed for the last two days pulled together into what may be expressed as leisure activities. However, she said that volunteer work could be leisure activity and she made the distinction between leisure and recreation. She feels that recreation is an activity rather than just leisure time; and leisure

is an attitude and the way that time is used. This is a highly individualized matter and each person must work it out for himself whether the individual is sighted, blind, blind diabetic, or whatever.

Leisure was further defined as that time that the individual has which is uncommitted. It was brought out that most blind people have more leisure time than do sighted people simply because many blind people do not secure employment as readily as a sighted person, therefore, he has more time doing little or nothing. It was agreed that this is a fact but at the same time the blind person and the blind diabetic must have his options as to how he or she wishes to use uncommitted time.

Leisure time can be destructive and unproductive. We often use the expression that we will put the blind or the blind diabetic person back into the community and she stressed the point that the blind diabetic should have never been taken out of the community. He or she should have been left in the community, understanding what the community has to offer and also having the community understand the blind diabetic. Following this concept, the blind diabetic can follow his life style in the community. The blind diabetic who goes through a traumatic period because of blindness and/or diabetes may have to be introduced back into the community because of the traumatic experience; this introduction is made when the client is ready and the determination of readiness requires professional skills.

There is a need for staff serving diabetics to understand the problems of blindness particularly if retinopathy is apparent. The experience by some agencies for the blind is that the staff working with diabetics deny the possibility of retinopathy. They never discuss blindness or the possibility of blindness resulting from diabetes; all they feel they need to know is how to teach a diabetic person to use a syringe for self-management of insulin. Ms. Gordon again stated that she was aware that she was raising questions that had been brought up for the last two days but she strongly felt that these questions all related to leisure time.

Recommendations for the American Foundation for the Blind

1. Encourage state legislators to make funds available for the blind diabetic now waiting for and/or receiving rehabilitative services.

2. Establish a working relationship with the six centers for diabetes established by the National Commission on Diabetes (now know as the National Council on Diabetes).

3. Develop a viable glucose urine testing device for use by blind diabetics.

4. Develop teaching seminars for medical staff working with diabetics so that they will learn to be reasonably comfortable in telling a diabetic that they may be blind.

5. Develop educational seminars for medical personnel in the area of blindness.

6. Develop teaching seminars for staff of agencies serving individuals who are blind and/or diabetic.

7. Hold additional seminars for staff in disciplines involved in providing services to blind diabetics.

8. Publish in journals; such as the Diabetic Educator and the Diabetic Care, articles related to blindness and diabetes.

9. Publish articles on blindness and diabetes in journals published by agencies for the blind.

10. Attend and participate in both national and regional meetings on diabetes such as those conducted by the American Diabetes Society.

11. Make more information available on the sexual problems of the diabetic. This should include education and counselling for a diabetic as well as for the professional dealing with diabetics.

12. Develop a research project related to the "caring system" in order to understand better the obstacles in the continuity of care and comprehensive care.

13. Develop a central system where all information related to blindness and diabetes would be available including information on diet, cook books, all devices such as insulin syringes and glucose urine analyzers.

14. Encourage rehabilitation centers serving diabetic blind persons to have available trained nutritionists or dietitians to help the blind diabetic in self-diet management.

15. Encourage the American Foundation for the Blind to hold national and/or regional workshops on diabetes and blindness for both rehabilitation and medical personnel.

16. Request the American Foundation for the Blind to make available on a national level a consultant on diabetes and blindness.

17. Encourage state agencies serving blind people to make services available to the diabetic with a prognosis of retinopathy long before the person reaches 20/200 or "legal blindness."

18. Make available through public service announcements information on diabetes and blindness.

19. Request federal legislators to earmark a specific percentage of funds to be available through federal legislation for services to blind diabetics.

20. Encourage agencies serving blind people to employ a specialist in rehabilitation who is thoroughly knowledgeable in diabetes and blindness.

21. Make diabetes and blindness one of AFB's major priorities for service.

22. Conduct a research study on the blind diabetic concept of the blindness system services and the way the blind diabetic is helped.

23. Address the problem of diabetes and blindness in the aging blind population giving particular attention to neuropathy and circulatory problems.

24. Encourage employers to request rehabilitative services for an employee who is diabetic and developing retinopathy before plans are made either to dismiss or retire the individual. This comes into the area of job retention.

APPENDIX I

Lecture, American Foundation of Blind
Donald M. Barnett, M. D.
October 31, Nov. 1 and 2, 1977

TREATMENT OF DIABETES IN CHILDHOOD AND ADOLESCENCE

Childhood and Adolescence complicated by a unique, acute-chronic illness of diabetes presents many treatment difficulties for the clinician. Doctor Priscilla White, who spent 50 years studying and treating this form of the disease, claimed that success in treatment depended upon both the changing degree of severity of diabetes and the changing attitude of the young toward diabetes.

Three Stages of Juvenile Diabetes in Youth (JODY)

I. Time of Onset
II. Time of Management
III. Time of Complications

I. Time of Onset:

a. JODY is the commonest endocrine disorder in childhood. JODY accounts for 5% of the total diabetic population but incidence varies with the time defined as "youth." (Fig. 1) JODY-like adult diabetes possible but the total cases of severe insulin dependency, at any age, does not exceed 10%.

b. Diagnosis of JODY usually made with marked classic symptoms (polys), often progressive, rapid weight loss and still not uncommonly in metabolic acidosis with or without "coma."

Recovery rapid with insulin and I.V. saline. Hypokalemia may be prominent, blood sugar less elevated and dehydration more severe than in adults. Degree of acidosis may not coincide with appearance.

Some degree of remission occurs in about 50% of cases often in the first month but lasts usually for months only and ends with continued linear growth and reproductive development (Table 1).

c. Child accepts diabetes with ease once symptoms cease. Insulin injections are not the problem that many adults claim they are for the patient. Adolescents are depressed from onset.

Parents present the major clinical challenge. The standard grief reaction in parents impedes instruction and the education often needs to be delayed. The Diabetic Treatment Unit at the New England Deaconess Hospital is an example of a source of support and transferred responsibility for parents at this time. To see healthy JODY adults and other parents "in the same boat" is most helpful. Parent-volunteers are an additional mechanism that is useful.

II. Time of Management:

Usually a decade or more follows the onset year of JODY where treatment centers around the patient alterations in patterns of daily living that are needed to accommodate diabetes. Lack of symptoms with hyperglycemia post Dx. is the largest factor in patient non-compliance with program.

Insulin: Dose needs to be increased as growth and pubescence proceed

Guideline:

Estimated Insulin Dose

1/2 ± unit	/ #	- onset
1/8 or 0u	/ #	- remission
1/3 to 1/2 unit	/ #	- pubescence - "intensification"
1/4 unit	/ #	- late adolescence-"stabilization"

This estimate will not work if diet is ad lib in carbohydrate; insulin injections are given into same hypertrophy area; illness ensues or activity approaches bedrest.

Approximately 2/3 of all JODY proceed to need night intermediate insulin by the 5th year duration in order to stop symptoms (too many reactions or nocturia) and/or to correct high fasting blood sugars. In this group, a pre-supper mix is often helpful in controlling post supper glycosuria. This multiple dose schedule has been proposed as a major reason for prevention of later vascular complications.

A low renal threshold in a majority of JODY during these years makes 2% Clinitest testing useless as a guide to M.D. or patient adjustments in insulin dose. Alternatives are: 2 gtt method, 6-12 hour block urines, Dextrostix and Hgb. A-1c determinations.

Hypoglycemia with rebound hyperglycemia confuses the regulation of "brittle" diabetic requiring careful decrease in the size of the offending insulin dose but most often needs the use of night intermediate insulin - "split" program.

Reactions without warning can appear but generally occur after 20 years duration JODY.

Diet: Calories should progress with increase in height and age by the same increments as in non-diabetic youth. After growth, calories are governed by ideal body weight (adult rules). Debate centers on per cent of carbohydrate, protein and fat, number of feedings emphasized and width of substitutions allowed. We use 40% carbohydrate, 20% protein and 35% fat, three meals - two snacks/day (mid-morning snack in grammar school age group) and extensive substitutions as long as the "meal" calculation conforms to above carbohydrate, protein, fat percentage. i.e., avoidance of most foods labelled "dietetic" but tonics allowed. 2 eggs/day, a staple of most diets of yesteryear down to 5/ week recommendation.

Obesity: Anthropologists point out that females normally "broaden" with menarche' and then reverse their hyperphagia to conform to adult stature and need. Diabetic girls remain hungry if allowed to continue to "eat up" to 1/3 to 1/2 unit /# requirements after regulation of menses. Readmission or change in summper camp emphasis is needed to prevent adult adiposity in this group) who already have enough reasons for low esteem.)

Sports: Activity predictions in childhood and adolescence are the same for diabetics - 1/3 very active "athletic", 1/3 moderately active, 1/3 sedentary. Erratic activity of this age group is expected but makes planning difficult with JODY.

Guideline:

Nominal sports or short duration vigorous activity require no change in the diet or insulin prescription. "Fast" carbohydrate (fruit juice, cola) before conditioned aerobic activity is a good idea. Sustained scrimmaging and hiking could require both additional carbohydrate supplements and 10-20% decrease in one or both of the doses of insulin. Ex.: Usual daily dose 8 regular, 36 lente but on day of mountain climbing, in well-controlled state, the dose could be 4 regular and 30 lente.

Formation: Self-esteem can predicatively take a plunge with the onset of diabetes. To make matters worse, if the pre-diagnosis time of development and the home/hospital/ school environment already has been poor, the child may have trouble surfacing at an expected rate and can "arrest" in psychological development.

Ideal Handling should include:

1. Optimistic and consistent doctoring with assurance that maximum treatment pays off and the future is improving.

2. Balanced parenting with indulgence and expectation graded by normal non-D.M. age related behavior.

3. Peer group experience preferably in a good summer camp environment.

4. Reinforcement of behavior with counselor-in-training and paramedical choices is helpful to youth. Good role model experience implied in this progression.

5. Strategic counselling especially if depression or acting-out behavior persists.

III. Time of Complications:

Prognosis regarding the morbidity and mortality of JODY is difficult because of: syndrome variability, quality of treatment, changing therapy and lack of prospective studies.

However, the following estimates seem clinically helpful at the present time.

1. Duration of JODY is the best guide to possible problems. Few long-term vascular/neuropathic complications occur before ten years of diabetes. Maximum insulinized JODY from onset has a striking lack of retinopathy and nephropathy.

2. By 20 years of diabetes mellitus (age 20-30 average) about 1/4 of the patients seem to experience serious retinopathy.

   a. This should be anticipated, prevention by tighter control and baselined with ophthalmological examination twice a year is very important in suspect patients between the 10-20th year of diabetes mellitus.

Clinical Example:

In 1977, a 23-year old woman was referred from the Eye Unit with 11 years of JODY and newly diagnosed neovascular retinopathy in right eye- some background retinopathy in the left eye. Finacé desired a large family and the physician's recommendation was to delay pregnancy planning, indefinitely, until laset treatment and follow-up could be assessed.

   b. Neovascular retinopathy predicts the possibility of nephropathy ensuing in 2-5 years. Hypertension if the clue- any rise in serum creatinine is the evidence.

3. 20-25% appear to have a life expectancy of 40 or more years relatively free of disabling complications.

4. Those patients who escape serious microvascular disease create a new population that needs clarification but CAD* is important determinant of outcome. Coronary artery disease is evident in 50% of the angiograms of the pilot transplant group discussed elsewhere and somewhat the same incidence can be inferred to the older and longer duration group of JOIY accounting for deaths in over 30-year age group. The clinical manifestations of the coronary disease are often absent and a high index of suspicion with duration of diabetes mellitus as guide is important.

Clinical Example:

In 1976, a 42-year old menstrating woman was sent to the Joslin Clinic with a complaint of shoulder and neck arthritis. DM diagnosed in 1939 at age 6 (duration 36 years) - no significant retinopathy seen. Suspicion of angina as factor in most of symptomology confirmed only after careful history taking, a distinctly positive treadmill test. Referring endocrinologist and house officers did not diagnose this problem.

*CAD = Coronary artery disease

Clinical Guideline: (important in elective surgery decisions)

JODY	Age	+	Duration	=	Coronary age
Example:	(above) 42	+	36 = 78	=	approximate life expectancy - coronary potential

Prevention of CAD is a priority for JODY and should follow the same rules as in the general population re: ↓ nicotine, conditioned exericse, limited dairy products early in life, etc.

5. Neuropathy in the form of debilitating pain is short-lived in JODY and is usually seen in the long-term grossly uncontrolled cases. Extremity lesions in JODY manifest more as neuropathic lesions while femoral artery disease is distinctly less apparent until 35 years of JODY. Neuropathic bladders, enteropathy and impotence can occur but seem much less common than in AODM*.

6. Retinopathy can run a continuous small incidence in all JODY despite duration but in these "survivors", it appears less often after 25 years of diabetes mellitus.

Clinical Example:

In 1976, a 63-year old patient with diabetes mellitus since 1924 was admitted to the Diabetes Treatment Unit with proliferating retinopathy that threatened vision. This meticulously-controlled grandmother had led a normal life. Four years earlier, she had had a successful coronary by-pass for unstable, progressive two-year duration angina.

Summary:

The Clinician who strives to give comprehensive care to this special group of diabetic patients can find it a challenging and satisfying assignment in every aspect of medical work whether it be diagnosis, therapeutics, education, counselling or research. Improvement by artificial devices, if technique is developed and even cure by gene manipulation or enzyme (s) alteration, if safe, is as eagerly awaited by physicians as the patient.

*AODM = Adult Onset Diabetes Mellitus

Figure I

JODY - AGE AT ONSET; JOSLIN CLINIC EXPERIENCE 1964 - 1973

(616 Female - 549 Male)

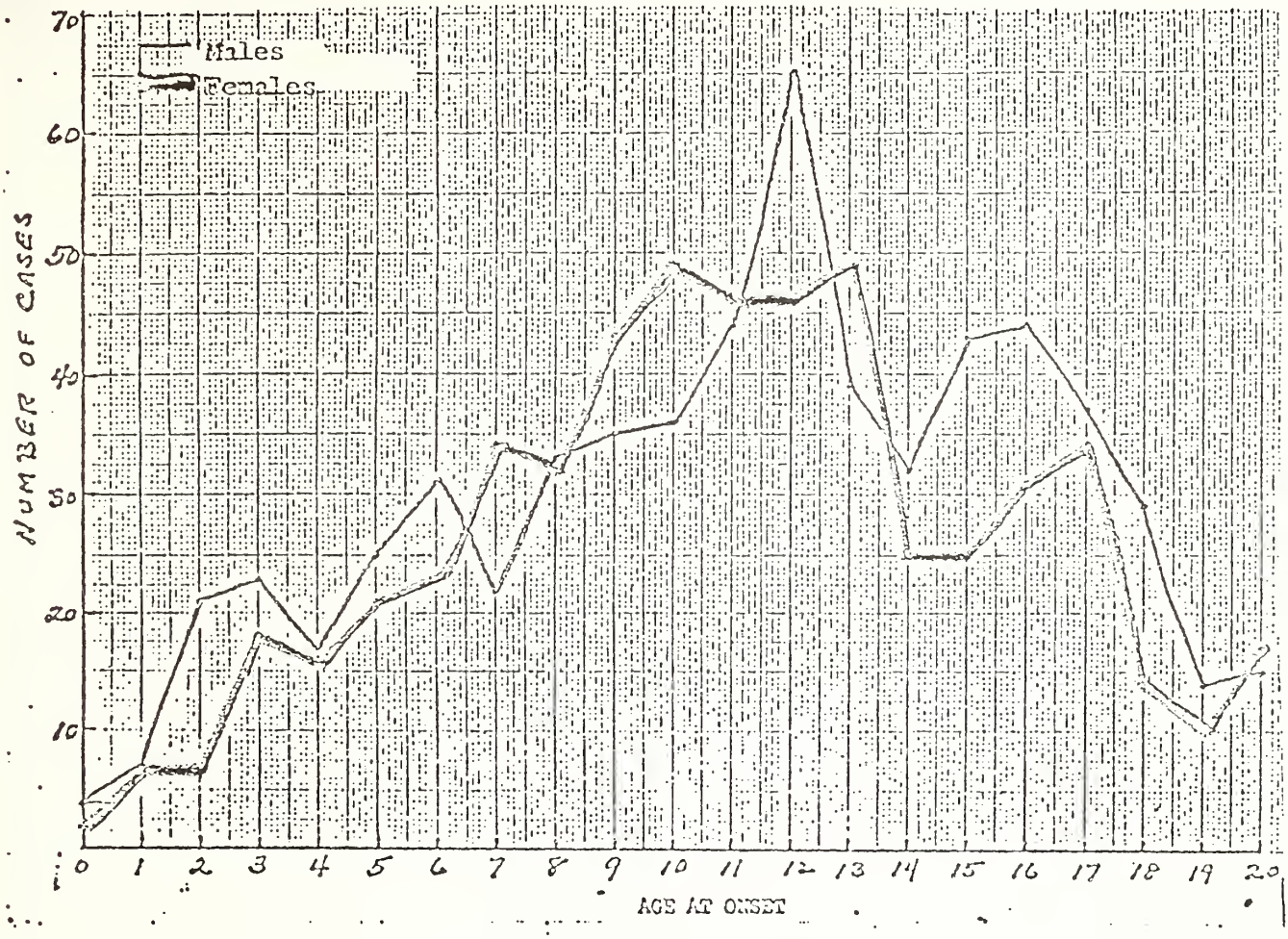

Table 1

STAGES OF DIABETES

Stage	Blood Insulin	Pancreatic insulin	Islet Cell Activity	Fasting Blood Sugar	Response to Sulfonylureas	Ins. treatment Inter-med.	Ins. treatment Rapid	Degree chemical Control Possible
1	+	+	+	normal	+	+	+	Perfect
2	+	+	+	Normal GTT	++	Token +	0	Perfect
3	↓	↓	↓	Sl.Elev.	↓	+	+	Good
4	0	0	0	High	0	+ 2x/d		Good
5	0	0	0	High	0	+ 2x/d	+ 2x/d	Good

Sandra Kolterman
Department of Rehabilitation
1111 Jackson Street # 5002
Oakland, California 94607

DIABETES AND BLINDNESS

Aid/Appliance	Description
Insulin Dosage Measurer Andros, Inc. 2302 4th Street Berkeley, California	Plastic easy to use device. For use only with U-100 B & D syringes. Can be used to mix dosage. $10.00
Insulin Syringe Filler Alvin C. Franklin Burbank, California 91504	Can be custom ordered for any type disposable syringe. Must accompany order with insulin type and syringe type used. Also manufactures needle guide for disposable syringes which is excellent. $8.50
Insulin Injector Daystrol - Scientific, Inc. 4018 West 65th Street Minneapolis, Minneapolis 55435	Automatically fills and injects insulin without a needle. However, cannot mix insulins or change doses. Needs to be sterilized only once per month. $395.00
Dos-Aid Filling Device American Foundation for the Blind 15 West 16th Street New York, New York 10011	Designed for use with Disposable syringes. Will accept most types of disposable syringes, but cannot be used to mix different types of insulin. MES563 $8.95
Automatic Injector B-D Bush Injector Available at most pharmacies	It holds only glassbarrel syringes and is a good learning tool for children and new diabetics as it is spring loaded and when the button is pushed, the needle automatically penetrates the injection site. $6.00

Aid/Appliance	Description
Instant Glucose Diabetes Society of Greater Cleveland 2022 Lee Road Cleveland, Ohio 44118	A handy, no-mess, way for diabetics to carry glucose with them to counteract insulin reaction. Instant glucose comes in convenient plastic tubes which can easily be opened and glucose can be put under tongue and absorbed quickly. Good for mobility instructors to carry when working with diabetics. Cost is $1.00 per tube and comes in packages of 3.
Large Print Embossed Labels Scotch 3 M Co. 320 Shaw Rd. S.San Francisco, California	Large print embossed labels for canned goods or any labeling. Good for diabetics who are unable to learn braille due to lack of sensitivity in fingers.
Insulgage Syringe Filler Meditec, Inc. 9485 E. Orchard Dr. Englewood,Colorado 80110	For use with B & D or Jelco disposable syringes. Availfor all strengths of insulin.
Syringe Magnifier GEMCO P.O. Box 55073	Plastic device which snaps onto any disposable syringe to enlarge unit scale. $30.00 per dozen.
Insulin Syringe Filler American Foundation for the Blind 15 West 16th Street New York, New York 10011	Made by Becton Dickinson Co. For use with glass syringe only. Must be sterilized daily. Has several parts - difficult to assemble. Not good for elderly patients. MES166 $14.50
Insulin Syringe American Foundation for the Blind 15 West 16th Street New York, New York 10011	Manufactured in West Germany. Device clicks and can be felt so is good for blind and deafblind. Each click is 2 units and is good for patients who change dosage as it resets each time. MES260 $19.95

Aids/Appliance	Description
Hill Accurate Dosage Insulin Syringe American Foundation for the Blind 15 West 16th Street New York, New York 10011	Glass syringe marked with U-80 scale only. Syringe is set by physician and when appropriate dose is filled, the syringe clicks. MES169 $6.95
Insulin Needle Guide American Foundation for the Blind 15 West 16th Street New York, New York 10011	Designed to fit top of Eli Lilly Insulin vials. Funnel shaped guides needle into rubber cap. Aluminin construction. MES168 $1.50
Insulin Needle Guide American Foundation for the Blind 15 West 16th Street New York, New York 10011	This guide can be made to fit your specific type of insulin vial. Is designed to help you locate the center of the insulin vial without blunting the needle. Needle guide should be sterilized before each use. Your empty insulin must be sent with order so that guide can be specially made to fit. $4.50
Disposable Syringes filled by a sighted person and stored	If only one type of insulin is used, these can be filled up to three weeks in advance. If a combination of two types is used, this can be done up to three weeks in advance only with U-100 insulin. If a combination of long acting and fast acting insulin is used, either U-40 or U-80, the syringe must be filled shortly before injection to prevent adverse settling reaction of the insulin.

Sandra Kolterman
1111 Jackson St. # 5002
Oakland, California 94607

WARNING SIGNS OF INSULIN REACTIONS

Excessive Hunger	Crying
Perspiration	Confusion
Pallor	Inability to Concentrate
Dizziness	Drowsiness or Fatigue
Headache	Poor Coordination
Nervousness or Trembling	Abdominal Pain or Nausea
Blurred Vision	Inappropriate Actions/Responses
Irritability	

TREATMENT

At the first sign of any of the above warning signs:

GIVE SUGAR IMMEDIATELY IN ONE OF THE FOLLOWING FORMS:

a. Sugar - 5 small cubes, 2 packets, or 2 teaspoons.

b. Fruit Juice - 1/2 to 3/4 cup.

c. Carbonated Beverages - (not diet or sugarless pop) 6 ounces.

d. Candy - 1/4 to 1/3 candy bar.

e. Instant Glucose - 1/2 tube. Available from: Diabetes Association of Greater Cleveland
2022 Lee Rd.
Cleveland, Ohio 44118
($1.00 per tube - comes 3 to a box.)

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834 Misson Street
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